Summary of Services for Youth with Special Health Care Needs in Kentucky



Family to Family Health Information Centers at the Commission for Children with Special Health Care Needs for health information http://chfs.ky.gov/ccshcn/parents.htm. West KY: (270) 852-2918 Louisville and East KY: (502) 429-4430 x 279

KY SPIN -- KY Special Parent Involvement Network - especially for information on education issues http://www.kyspin.com/ 1-800-525-7746

United Partners in Kentucky (UP in KY) www.up-in-ky.com offers links to many services in Kentucky

FIND of Louisville: (Family Information Network on Disabilities) www.findoflouisville.org

Transition One Stop: Find transition information across the lifespan for KY at www.transitiononestop.org

Assistance KY web site is a one-stop shop to help connect you to financial assistance, stay healthy, take care of your children, stay in your home and to assist you with job resources http://assistance.ky.gov/

Health Care in Kentucky

	Fare in Kentucky		
Contacts	Comments		
Commission for Children with Special Health Care Needs 310 Whittington Parkway, Suite 200 Louisville KY 40222 Phone (502) 429-4430 1-800-232-1160 http://chfs.ky.gov/ccshcn	 12 District Offices Specialty clinics, care coordination, referral Family resources and transition programming Adult program for hemophilia 		
Local health departments: Call (502) 564-4830 for information in your area: Fayette County: (859) 252-2371 http://www.khda-ky.org/countymap.htm#lexington-fayette Jefferson County: (502) 574-6530 http://www.khda-ky.org/countymap.htm#jefferson	 Offer a variety of maternal and child health and family services including family planning, well-child checkups, immunizations, nutrition, genetic and developmental evaluation, home health (services vary) 		
Home Health Agencies and Hospices; for information call KY Home Health Association at http://www.khha.org/ (859) 268-2574 or 1-800-832-4036	 Provide homemakers, home health aids, in-home nursing care, medical equipment Hospice provides services for children with chronic conditions and adults with terminal illness and their families 		
Comprehensive Care Centers: check phone book under Mental health or Mental Retardation and Services for Developmentally Disabled: State Office: (502) 564-4527 http://mhmr.ky.gov/kdmhmrs/default.asp	 Provide evaluations, counseling and referral for mental illness, mental retardation, drug and alcohol rehab, and psychosocial concerns Variety of programs for children, teens, parents 		
Health Kentucky: Hot Line - 1-800-633-8100 Kentucky Physician's Care: http://www.healthkentucky.org/	Health care for Kentucky citizens who are uninsured and do not qualify for government programs		
Shriners Hospitals for Children 1900 Richmond Road, Lexington, KY 40502 (859) 266-2101 http://www.shrinershq.org/Hospitals/Lexington/	 Comprehensive inpatient and outpatient treatment of orthopedic problems and related conditions for ages birth to 21; Cincinnati hospital cares for children and youth who have been burned 		
Easter Seals Society of KY (859) 254-5701 or 1-800-233-3260 http://www.cardinalhill.org	 Services children and adults with disabilities Cardinal Hill Rehabilitation Hospital Camp KYSOC and Information and Referral 		
University of Kentucky Medical Center Phone: (859) 323-5000 UK Health Connection (859) 257-1000 or 1-800-333-8874 http://www.mc.uky.edu/	Specialized services for variety of medical conditions		
University of Louisville Medical Center Phone: (502) 562-3775 http://www.louisville.edu/hsc/ U of L Child Evaluation Center	Specialized services for variety of medical conditions		

Home of the Innocents (502) 561-6600 www.homeoftheinnocents.org	•	Residential care for children with disabilities; teen and family counseling
Acquired Brain Injury Waiver Program: (502) 564-5198 or Toll Free: (866) 878-2626 http://chfs.ky.gov/dms/Acquired+Brain+Injury.htm	•	Case management and a wide range of services and funding sources Rehabilitative home and community based services to individuals with a brain injury as an alternative to nursing facility services so the individual can return to the community with existing resources.
Brain Injury Association of KY http://www.biak.us/ Brain Injury Benefits Program: 1-800-447-4984 http://www.kybraininjuryfund.org/	•	Case management and a wide range of services and funding sources
Kentucky Voices for Health www.kyvoicesforhealth.org	•	A coalition of concerned Kentuckians who believe that the best health care solutions are found when everyone works together to build them

Health Care and Other Financial Resources in Kentucky

Contacts	Comments
Department for Medicaid Services: contact Department for Community Based Services (previously Department for Social InsuranceDSI office) in county of residence (800) 205-4696 http://chfs.ky.gov/dms/	 Based on family income; spend down; disabled child calculation; and/or home and community based waiver program Services include: office visits, dental care, immunizations, mental health, pharmacy, vision care, hospital care and much more.
EPSDT (Early and Periodic Screening, Diagnosis, and Treatment) program: Contact Medicaid office EPSDT Special Services: (502) 564-6890 http://chfs.ky.gov/dms/epsdt.htm	 Funds screening and medically necessary services not normally funded by Medicaid
KCHIP (see contact info under Medicaid) 1-877-KCHIP18 or contact local DCBS office http://kidshealth.ky.gov/en/	 Health insurance for children birth to 19 whose family income is less than 200% of poverty (approx. \$35,000 for family of 4 in 2009) and who are not eligible for Medicaid Benefits are the same as with Medicaid
Medicaid Waiver Services: contact Medicaid office (502) 564-5560: http://chfs.ky.gov/dms/mws	 Provide home and community support services to keep persons with disabilities out of institutions Waivers for specific conditions such as brain injury or developmental disabilities; also consumer-directed options
Cabinet for Families and Children Ombudsman 1-800-372-2973 or 1-800-627-4702 (TTY) (502) 564-5497	 Assists with issues related to programs administrated by the Cabinet including TANF, food stamps, Medicaid/KCHIP eligibility, foster care, etc.
KY Association for Community Action: 1-800-456-3452 www.kaca.org	 The Community Action Kentucky network provides low and moderate income Kentuckians a variety of services including weatherization, Head Start, employment and self sufficiency training, Low Income Home Energy Assistance Program, transportation, senior services, and more

Contacts	Comments
Office of Vocational Rehabilitation: Workforce Development Cabinet: 1-888-420-9874 http://ovr.ky.gov	 Vocational assessment, referral, training, and work placement for people with disabilities Assistive Technology loan program
Carl D. Perkins Vocational Training Center: Thelma, KY http://ovr.ky.gov/cdpvtc/	 The services are designed to prepare individuals for employment and to improve independent living functioning through education, medical, technology, and related programs Services available: vocational assessment, work adjustment, and vocational training; rehabilitation counseling; comprehensive medical rehabilitation services; psychological services; recreational activities; brain injury services; speech and language communication services
Wendell Foster Campus for Developmental Disabilities: Owensboro, KY http://www.wkatc.org/ http://www.wkatc.org/assistive_technology_center/	 The center offers Residential Living ,Supports for Community Living, Day Care, Sensory Park, Out Patients Therapy (Speech, OT, PT), Kelly Autism Center, Respite Care Services in House Western Kentucky Assistive Technology Center
ADA in Kentucky: 1-877-432-2933 http://ada.ky.gov/	 Information about Americans with Disabilities Act laws and their implementation in Kentucky and links to services for people with disabilities.

KATS (Kentucky Assistive Technology Services Network) 1-800-327-5287; www.katsnet.org	 Assistive technologies and related services for all Kentuckians with disabilities including referral to public and private agencies for services and funding
Goodwill Industries: 1-800-889-8775 http://www.gwik.org/	 Assistance in finding employment Discount stores
Southeast Disability & Business Technical Assistance Center: 1-800-949-4232 (V/TTY/Spanish) www.sedbtac.org	One of ten regional ADA & I T Centers funded by NIDRR to provide training, technical assistance, and materials for families and professionals
Find – A – Future http://www.findafuture.org/Provider/viewproviders.asp	 Web site developed to increase the level of awareness of parents, families, school personnel, and services providers of the services and supports available to students transitioning from school to the world of work/adult programs and to increase participation in appropriate programs.
Volunteers of America: Lexington: (859) 254-3469; Louisville: (502) 636-0771 http://www.voaky.org	 Services for homeless including an independent living program, temporary housing, life skills training, job training
OWL (Opportunity Workshop of Lexington): (859) 254-0576 www.owlinc.net	Job training and placement in Lexington area
Kentuckiana Works (502) 574-2500 http://www.kentuckianaworks.org/	 Employment for at-risk youth in Jefferson and surrounding counties Youth initiatives for ages 14-21
Community Volunteerism & National Service Kentucky Commission on Community Volunteerism & Services (KCCVS) 1-800-239-7404 www.volunteerKY.ky.gov	 KCCVS administers Kentucky's AmeriCorps*State and related national services programs. Kentucky provides the services of a disabilities coordinator as part of KCCVS' commitment to disabilities inclusion. AmeriCorps members serve with projects like Habitat for Humanity, the American Red Cross, Boys and Girls Clubs and many more local and national organizations. AmeriCorps members train volunteers, tutor and mentor at-risk youth, build housing, clean up rivers and streams, help seniors live independently, provide emergency and long-term assistance to victims of natural disasters and meet other community needs.

Independence Building, Housing, Transportation, Personal Assistance, Respite, and Recreation in Kentucky

Respite, and Recreation in Kentucky		
Contacts	Comments	
Centers for Independent Living: http://www.ilru.org/html/publications/directory/kentucky.ht ml Bowling Green: Disability Resource Initiative (270) 796-5992 Covington: Disabilities Coalition of N. KY (859) 431-7668 Harlan: Pathfinders for Independent Living: (606) 573-5777 Lexington: Independence Place (859) 266-280 Louisville: Center for Accessible Living: (502) 589-6620 http://www.calky.org/. Murray: Center for Accessible Living (270) 753-7676	 Information and referral related to housing, transportation, work, personal assistance, education, recreation, legal issues for people with disabilities Information on assistive technology loan programs, housing modification plans and funds, ADA rights and responsibilities SSI benefits and work incentives counselors 	
Supported Living: (502) 564-7702 http://mhmr.ky.gov/mr/supportedliving.asp?sub1	Several programs to provide home modifications, supported employment, therapies, residential supports, emergency response systems, specialized medical equipment and assistive technology	
ARC of Kentucky: (502) 875-5225 or 1-800-281-1ARC http://arcofky.org/	 Programs and referral for people with developmental disabilities "KEEPSAKE" A Family to Family Resource Guide to Services & Opportunities for Kentuckians with Special Health Care Needs and Their Families 	
Kentucky Partnership for Families and Children Office of Family Leadership, Department of Mental Health 1-800-369-0533; www.kypartnership.org	 Provides a united voice for parents, families, and organizations dedicated to improving services for children with mental, emotional, and behavioral disorders. 	
KY Council on Developmental Disabilities: 1-877-367-5332; http://chfs.ky.gov/kcdd/	Information and advocacy for people with developmental disabilities	
KY Protection and Advocacy: 1-800-372-2988 http://www.kypa.net/	Provides information and advocacy services for individuals whose rights have been violated due to a disability	

KY State ID card: From Circuit Court Clerk's Office in County of residence; http://drlic.kytc.ky.gov/general/general.htm	 Bring birth certificate, social security card, something with address; costs \$12 and is good for 4 years
Transportation: start with public transportation system in your city or county; for training and modification for people with disabilities, call Vocational Rehabilitation 1-800-372-7172: http://ovr.ky.gov	 Paratransit cards; For vehicle modification consultations, call Superior Conversions Paul L. Erway, Rehab consultant 1-800-458-8267 (offices in Louisville and Lexington)
Kentucky Transportation Cabinet (502) 564-7433 http://www.kytc.state.ky.us/ http://transportation.ky.gov/	Information on specialized public transportation systems
Kentucky Housing Authority: (502) 582-5251 http://www.hud.gov/local/ky/	 Housing assistance for rent, utility, and security deposit; provides information on supportive housing programs and programs that lead to home ownership
Local housing authorities, local public libraries, local YWCA and YMCA, churches	 Programs for people with disabilities including residential programs, fitness programs, camps, educational, counseling and social work services
Neighborhood Places in Louisville: (502) 574-8000 http://www.louisvilleky.gov/NeighborhoodPlace	 Partnership of agencies and community residents who have come together to deliver services blended and accessible health, education, employment and human services in Louisville Metro.
Salvation Army: Lexington: (859) 252-7706 http://www.salvationarmy-lex.org Louisville: (502) 583-5191 http://www.uss.salvationarmy.org/louisville	 Local groups have shelters, food and clothing assistance, youth recreation and mentoring programs Health clinics, counseling
Parks and Recreation Departments in cities and counties	 Recreational programs for people of all ages; many include people with disabilities or have special programs for people with disabilities
Central Kentucky Riding for the Handicapped (859) 231-7066: http://www.ckrh.org	Horseback riding for children with handicaps at the Kentucky Horse Park
Dream Riders of Kentucky, Philpot, KY (Owensboro) www.dreamridersofky.org	 Dream Riders of Kentucky is a non-profit organization providing therapeutic and recreational horseback riding for individuals with physical and mental disabilities free of charge
KEAC (Kentucky Equine Abilities Center) Madisonville, KY www.northstarsporthorsesllc.com	Therapeutic riding at NorthStar SportHorses LLC Farm
Center for Courageous Kids, Scottville, KY http://www.courageouskids.org/	 The Center for Courageous Kids® is a world-class medical camp at no cost to families designed specifically for children living with medical challenges Family weekend retreats and 9 separate weeks of illness specific summer camping sessions focused specifically on the ill child
Two Rivers Buddy Ball, Owensboro, KY http://www.tworiversbuddyball.com/	 Non-profit sports league for kids ages 5-20 with any disability mental or physical that would keep them from playing on a regular league Fishing tournaments, bowling, baseball, basketball, soccer, cheerleading
YMCA and YWCA and 4-H; Girl Scouts, Boy Scouts; Big Brothers/Big Sisters: (859) 233-4460 in Lexington United Way of Kentucky: www.uwky.org	 Recreation programs and camps for all ages many focusing on independence building and mentoring United Way has 211 telephone number that connects callers with services
Arts Programs in KY: http://artscouncil.ky.gov/links/kyorgs.htm	 Variety of arts programs some of which work with people with disabilities Latitude Arts: Art training and studios for people with disabilities (based in Lexington)
Very Special Arts: (502) 556-3775 (V/TTY Frankfort) 1-877-781-8725 Bowling Green; http://www.vsartsky.org/	 Through the arts, VSA of Kentucky provides opportunities for people with disabilities to be part of the life of their communities and make our world more accessible and enjoyable. Arts education, community arts programming, and
	professional development are vital elements of our service to Kentucky.

School and Higher Education in Kentucky

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Contacts	Comments
Local public schools: Call director of special education at local school or state Dept of Ed at 1-800-533-5372: www.education.ky.gov ; Some schools have Family Resource and Youth Service Centers and/ or Special Education Parent Resource Centers: http://chfs.ky.gov/dfrcvs/frysc/ (502) 564-4986	 Under IDEA (Individuals with Disabilities Act) schools provide free, appropriate public education to children with disabilities Mainstreamed children are protected by the Americans with Disabilities acts (ADA) to have reasonable accommodations for education through 504 plans
School to Work Programs: contact your local school system: (502) 564-5901	Offer shadowing and work experiences for all students

Higher education in Kentucky: www.gohigherky.org Community Colleges, Technical Schools, Colleges and Universities have Disability Coordinators: 1-877-528-2748 or http://www.kctcs.edu Contact specific colleges for more information	Colleges and technical schools have support services for students with disabilities requesting accommodations for physical, emotional, and/or learning disabilities
Kentucky Higher Education Assistance Authority (KHEAA) 1-800-928-8926 www.kheaa.com	 Information about various scholarships, loans, grants, work-study to KY colleges
University of Kentucky, Human Development Institute (859) 257-1254 http://www.hdi.uky.edu/Home.aspx ; Find the Disability Resource Manual at: http://www.hdi.uky.edu/filesfromDaniel/HDI_kydrm-8-08.pdf http://www.hdi.uky.edu/ProductsAndResources.aspx Commission on the Deaf and Hard of Hearing	 Comprehensive diagnostic evaluations and treatment or program recommendations; assistive technology evaluations Teacher training School transition programming and evaluation Website with resources on transitions across the lifespan Resource Manual (2008) Advocates for children and adults who are deaf and hard of hearing
1-800-372-2907 (V/TDD) http://www.kcdhh.ky.gov/	 Provides information and referral services TTY distribution program
KY School for the Deaf (Danville): (859) 239-7017 http://www.ksd.k12.ky.us/	 Assessment, counseling, referral, residential school programs for youth with hearing impairments
KY Department for the Blind: 1-800-321-6668 http://blind.ky.gov/	Information, referral, and advocacy for people with vision impairments
KY School for the Blind (Louisville): (502) 897-1583 http://www.ksb.k12.ky.us/	 Assessment, counseling, referral and residential school programs for visually impaired youth
Christian Appalachian Project: 1-866-270-4227 toll-free http://www.christianapp.org/	 Provides variety of educational, counseling, children and youth and adult learning services for people in Eastern Kentucky
	Information and Support Services
National	Information and Support Services Kentucky
National Autism Society: 1-800-3AUTISM www.autism-society.org	Kentucky Kentucky's Family Guide to Autism Spectrum Disorders
National Autism Society: 1-800-3AUTISM	Kentucky Kentucky's Family Guide to Autism Spectrum Disorders https://louisville.edu/education/kyautismtraining/resources/family-guide Kentucky Autism Services and Supports https://katcproviders.louisville.edu
National Autism Society: 1-800-3AUTISM www.autism-society.org Epilepsy Foundation: http://www.epilepsyfoundation.org/ Project Access transition programming	Kentucky Kentucky's Family Guide to Autism Spectrum Disorders https://louisville.edu/education/kyautismtraining/resources/family-guide Kentucky Autism Services and Supports http://katcproviders.louisville.edu online provider guide that is search-able by region. Epilepsy Foundation Kentuckiana Louisville, KY (502) 637-4440 or (866) 275-1078 http://www.epilepsyfoundation.org/kentuckiana/ www.kyhemo.org (502) 456-3233
National Autism Society: 1-800-3AUTISM www.autism-society.org Epilepsy Foundation: http://www.epilepsyfoundation.org/ Project Access transition programming http://www.epilepsyfoundation.org/projectaccess/ Hemophilia Foundation:	Kentucky Kentucky's Family Guide to Autism Spectrum Disorders https://louisville.edu/education/kyautismtraining/resources/family-guide Kentucky Autism Services and Supports http://katcproviders.louisville.edu online provider guide that is search-able by region. Epilepsy Foundation Kentuckiana Louisville, KY (502) 637-4440 or (866) 275-1078 http://www.epilepsyfoundation.org/kentuckiana/
National Autism Society: 1-800-3AUTISM www.autism-society.org Epilepsy Foundation: http://www.epilepsyfoundation.org/ Project Access transition programming http://www.epilepsyfoundation.org/projectaccess/ Hemophilia Foundation: http://www.hemophilia.org/ Sickle Cell Disease Association of America	Kentucky Kentucky's Family Guide to Autism Spectrum Disorders https://louisville.edu/education/kyautismtraining/resources/family-guide Kentucky Autism Services and Supports http://katcproviders.louisville.edu online provider guide that is search-able by region. Epilepsy Foundation Kentuckiana Louisville, KY (502) 637-4440 or (866) 275-1078 http://www.epilepsyfoundation.org/kentuckiana/ www.kyhemo.org (502) 456-3233
National Autism Society: 1-800-3AUTISM www.autism-society.org Epilepsy Foundation: http://www.epilepsyfoundation.org/ Project Access transition programming http://www.epilepsyfoundation.org/projectaccess/ Hemophilia Foundation: http://www.hemophilia.org/ Sickle Cell Disease Association of America www.sicklecelldisease.org/ Spina Bifida Association of America	Kentucky Kentucky's Family Guide to Autism Spectrum Disorders https://louisville.edu/education/kyautismtraining/resources/family-guide Kentucky Autism Services and Supports http://katcproviders.louisville.edu online provider guide that is search-able by region. Epilepsy Foundation Kentuckiana Louisville, KY (502) 637-4440 or (866) 275-1078 http://www.epilepsyfoundation.org/kentuckiana/ www.kyhemo.org (502) 456-3233 No KY member organization KY: http://www.sbak.org/

Updated September 10, 2010 KY Commission for CSHCN Shriners Hospitals for Children, Lexington University of Kentucky Human Development Institute



National Resources

Disability.Gov National portal for disability information http://www.disability.gov/	Resources on a variety of issues for people with disabilities of all ages
Government Benefits: Online www.govbenefits.gov	A comprehensive source on federal government benefits
Social Security Administration: Social Security cards; Work Incentive Plans; Supplemental Security Income (SSI): 1-800-772-1213 www.socialsecurity.gov Especially for youth: www.socialsecurity.gov/work/youth.html and http://www.ssa.gov/kids/	A number of programs which help people with disabilities get higher education, training, accommodations, work experience without losing SSI and Medicaid benefits including PASS, 1619a and b, IWRP, IPE, Student Earned Income Exclusion; IWRE Information useful to Social Security beneficiaries related to Ticket to Work, PASS and other work incentives
SSA: The Benefit Eligibility Screening Tool (BEST) http://www.ssa.gov/ssi/ To find SSA Benefits counselors and state information: https://secure.ssa.gov/apps10/oesp/providers.nsf/bystate	 Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues (not Social Security taxes) It is designed to help aged, blind, and disabled people, who have little or no income; and It provides cash to meet basic needs for food, clothing, and shelter
SSA: State by State https://secure.ssa.gov/apps10/oesp/providers.nsf/bystate	 State by state listing of resources such as VR, WIPA, Ticket to Work, Protection and Advocacy
Ticket to Work: www.yourtickettowork.com/	 Ticket to work program information for SSI beneficiaries and providers of work opportunities
Job Accommodation Network 1-800-526-7234; http://janweb.icdi.wvu.edu/	 U.S. Department of Labor's Office of Disability Employment Policy (ODEP) service.; answers questions on accommodations and employment for workers with disabilities.
Workforce Development Department of Labor Office - Disability Employment Policy: www.dol.gov/odep/ www.ncwd-youth.info	 Programs and statistics on employment of people with disabilities NCWD/Youth is source for information about employment and youth with disabilities. Experts in disability, education, employment, and workforce development strive to ensure the highest quality, most relevant information available.
Vocational Rehabilitation: www.ed.gov/about/contacts/state/index.html?src=gu	State information on contacts and statistics about education and vocational rehabilitation
Transportation: <u>www.disability.gov/transportation</u>	 Freedom to Travel Independently Across Town or Across the Country: information about accessible transportation systems
Housing: www.disability.gov/housing Centers for Independent Living: www.ilru.org/html/publications/directory/index.html	 General and state information on housing for people with disabilities Map offering information on state CILs
Assistive Technology: Abledata www.abledata.com	 Information about assistive technology devices from the National Institute on Disability and Rehabilitation Research, US Department of Education
Fitness: National Center on Physical Activity and Disability: http://www.ncpad.org/	Information from the University of Illinois at Chicago about the relationship between physical activity and healthy outcomes
National Respite Network and Resource Center http://chtop.org/ARCH.html	Information and referral about respite services and funding; includes national respite service locator
Resources for Families of Children with Disabilities http://www.supportforfamilies.org/resources.html	Parent-run San Francisco-based nonprofit organization
	cation Resources
National Dissemination Center for Children with Disabilities (NICHCY): www.nichcy.org State pages of resources:	 Serves the nation as a central source of information on: disabilities in infants, toddlers, children, and youth, IDEA, which is the law authorizing special education, No Child Left Behind (as it relates to children with disabilities), and

www.nichcy.org/Pages/StateSpecificInfo.aspx	research-based information on effective educational practices.
Higher Education Opportunities Act: http://www.ed.gov/policy/highered/leg/hea08/index.html	Information on many aspects of high education including funding opportunities
National Center on Secondary Education and Transition (NCSET): www.ncset.org/	• The National Center on Secondary Education and Transition (NCSET) located at the University of Minnesota provides technical assistance and disseminates information focused on providing students with disabilities with improved access and success in the secondary education curriculum; ensuring that students achieve positive postschool results in accessing postsecondary education, meaningful employment, independent living and participation in all aspects of community life; supporting student and family participation in educational and postschool decision making and planning; and improving collaboration and system linkages at all levels through the development of broad-based partnerships and networks at the national, state, and local levels.
National Secondary Transition Technical Assistance Center (NSTTAC): www.nsttac.org/	• In order to ensure full implementation of IDEA and help youth with disabilities and their families achieve desired post-school outcomes, NSTTAC located at UNC-Charlotte helps states build capacity to support and improve transition planning, services, and outcomes for youth with disabilities and disseminate information and provide technical assistance on scientifically-based research practices with an emphasis on building and sustaining state-level infrastructures of support and district-level demonstrations of effective transition methods for youth with disabilities.
	d Child Health Bureau National Resource Centers Youth with Special Needs
Transition	Center that focuses on understanding systems, access to quality health
Healthy & Ready to Work www.hrtw.org	care, and increasing the involvement of youth. Tools, information, and
Project ended June 2010; website still available	resources for youth, families, health care providers and others interested in transition to adulthood including a transition bibliography and list of data sources; located at Maine Children with Special Needs
New project: National Health Care Transition Center for Youth with	agency
Special Health Care Needs http://www.medicalhomeimprovement.org/pdf/CMHI%20a warded%202millionFinal.pdf	New project located at Center for Medical Home Improvement, Concord, NH
Communities organized: Champions for Inclusive Communities www.championsinc.org Project ended June 2010	National center designed to support communities in organizing services for families of children and youth with special health care needs (CYSHCN) located at Utah State University
See: http://www.eiri.usu.edu/projects/champions/	 New project funded June 2010 located in Massachusetts – no website as of Sept 2010
Screening	Screening Initiatives focusing on transition skills:
-	Bright Futures screening tools for birth through young adulthood:
Newborn & Genetics:	www.brightfutures.aap.org
http://genes-r-us.uthscsa.edu/ Newborn Hearing:	 AMA GAPS (Guidelines for Adolescent Preventive Services) http://www.ama-assn.org/ama/pub/physician-resources/public-
http://www.infanthearing.org/	health/promoting-healthy-lifestyles/adolescent-health/guidelines-
	adolescent-preventive-services.shtml
	Jacksonville Health and Transition Services (JaxHATS)
	 Jacksonville Health and Transition Services (JaxHATS) http://www.jaxhats.ufl.edu/
	 Jacksonville Health and Transition Services (JaxHATS) http://www.jaxhats.ufl.edu/ U.S. Preventive Services Task Force: recommendations about clinical preventive services, including screenings, counseling, and preventive medications for all ages http://www.ahrq.gov/clinic/USpstfix.htm
Youth and Family Involvement	Jacksonville Health and Transition Services (JaxHATS) http://www.jaxhats.ufl.edu/ U.S. Preventive Services Task Force: recommendations about clinical preventive services, including screenings, counseling, and preventive medications for all ages http://www.ahrq.gov/clinic/USpstfix.htm Other Youth and Family Resources:
Family Voices – National Center for	Jacksonville Health and Transition Services (JaxHATS) http://www.jaxhats.ufl.edu/ U.S. Preventive Services Task Force: recommendations about clinical preventive services, including screenings, counseling, and preventive medications for all ages http://www.ahrq.gov/clinic/USpstfix.htm Other Youth and Family Resources: Family Village: www.familyvillage.wisc.edu Information for children
Family Voices – National Center for Parent/Professional Partnerships	Jacksonville Health and Transition Services (JaxHATS) http://www.jaxhats.ufl.edu/ U.S. Preventive Services Task Force: recommendations about clinical preventive services, including screenings, counseling, and preventive medications for all ages http://www.ahrq.gov/clinic/USpstfix.htm Other Youth and Family Resources: Family Village: www.familyvillage.wisc.edu Information for children and adults with disabilities. Supported by Waisman Center at the
Family Voices – National Center for	Jacksonville Health and Transition Services (JaxHATS) http://www.jaxhats.ufl.edu/ U.S. Preventive Services Task Force: recommendations about clinical preventive services, including screenings, counseling, and preventive medications for all ages http://www.ahrq.gov/clinic/USpstfix.htm Other Youth and Family Resources: Family Village: www.familyvillage.wisc.edu Information for children

http://www.familyvoices.org/info/ncfpp/f2fhic.php Youth Leadership Forums: www.dol.gov/odep/programs/vouth.htm Family Voices - KASA - Kids as Self and http://www.aylf.net/chapters.html Advocates: www.fvkasa.org A group that Based on a highly successful program of Youth Leadership Forums promotes self advocacy among youth with (YLF) in California, the long-term goal of the program is to replicate this special health care needs training in all 50 states. See NCSET brief: http://www.ncset.org/publications/viewdesc.asp?id=2845 www.familyvillage.wisc.edu Waisman Center at the University of Wisconsin site with links to a variety of information on children and youth with disabilities **Medical Home** Other Medical Home and Transition Resources National Center for Medical Home AAP: Health Care for College Students: www.aap.org/publiced/BR Teen College.htm Implementation www.medicalhomeinfo.org AAP's user-friendly website: www.HealthyChildren.org State by State Information: http://www.medicalhomeinfo.org/states/index.html Society for Adolescent Medicine: The Healthy Student: A Parent's The National Center at the American Academy of Guide to Preparing Teens for the College Years Pediatrics provides medical home resources, technical http://www.adolescenthealth.org/AM/Template.cfm?Section=Health Inf assistance and support to physicians, families, and other o for Teens&Template=/CM/ContentDisplay.cfm&ContentID=1668 medical and non-medical providers who care for children. The Healthy Student: www.adolescenthealth.org/The _Healthy_Student.pdf National Center for Medical Home Improvement: website has lots of downloadable teaching materials including site for www.medicalhomeimprovement.org teens; is linked to www.KidsHealth.org The mission of the Center for Medical Home Improvement www.healthfinder.gov Great place to find information on various (CMHI) located at NH's Crotched Mountain Foundation conditions/diseases and health promotion information and Rehabilitation Center is to promote high quality Mental health: www.mentalhealth.org primary care in the medical home and secure health www.strengthofus.org NAMI Social Networking Site for Young Adults. policy changes critical to the future of primary care a user-driven social networking community where members can connect with peers, share personal stories, creativity and helpful resources University of Washington Adolescent Health Project Insurance Other Insurance information sources: Catalyst Center for Improving Financing of Care for Department of Labor- Health Plan: www.dol.gov/dol/topic/health-Children and Youth with Special Health Care Needs plans/planinformation.htm www.hdwg.org/catalyst/ Government general health insurance: www.usa.gov/Citizen/Topics/Health/HealthInsurance.shtml The Catalyst Center is dedicated to improving health care National Conference of State Legislatures coverage and financing for Children and Youth with www.ncsl.org/programs/health/dependentstatus.htm Special Health Care Needs (CYSHCN) based at Boston State-by state information about health care coverage for youth University School of Public Health through parental health insurance policies National Association of Insurance Commissioners www.naic.org/state web map.htm Links to all state offices of commissioners of insurance **National Center for Cultural Competence** The mission of the National Center for Cultural Competence is to www11.georgetown.edu/research/gucchd/nccc/ increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities, and to promote health and mental health equity; located at Georgetown University

CAHMI: Child and Adolescent Health

Measurement Initiative: www.cshcndata.org

Updated September 10, 2010
KY Commission for CSHCN, Shriners Hospitals for Children, Lexington
University of Kentucky Human Development Institute

Data from the National Survey of Children with Special Health Care

Needs and the National Survey of Children's Health from the Data Resource Center based at the Oregon Health & Science University